Ageing & Society **22**, 2002, 399–418. © 2002 Cambridge University Press
DOI: 10.1017/S0144686X02008759 Printed in the United Kingdom

Elderly people's accounts of home care rationing: missing voices in long-term care policy debates

JANE ARONSON*

ABSTRACT
Fundamental shifts in state intervention in recent years have resulted in steady curtailment in public provision of community and social care. A longitudinal study of elderly women receiving home care in Ontario explored the reverberations of these shifts in the texture of frail elderly people's lives. Three distinct accounts of negotiating unstable and rationed home care were discernible. *Taking charge* was an active account of women successfully impressing their particular needs and identities on home care provision. *Pushed over the edge* was a vulnerable account of insufficient and depersonalised care in which participants felt themselves practically and emotionally out of control. In *Restraining expectations*, women adjusted silently to the shortcomings of home care, stoically making themselves smaller as they found their previous orbits and identities unsupported. Home care's front line emerged as a complex site of struggle for identity and agency – a struggle in which elderly people engage with inventiveness and determination but also with dwindling support, few witnesses and in mounting isolation.

KEY WORDS **–** rationed social care, identity, entitlement, community care/home care policies, Canada.

Introduction

Community care for frail elderly people has long promised personalised support for independent living although it has, typically, been a poorly funded and marginal area of health and social programming (Barnes 1997). The long-standing limitations of community care have intersected in recent years with fundamental retreats in state interventions and social programmes, taken up in different forms across welfare jurisdictions. These broad political and ideological shifts have resulted in a steady curtailment in public provision of community and social care (Aronson and Neysmith 2001; Dalley 1998; Glendinning 1998). The reverberations of these large shifts in the texture of frail

* School of Social Work, McMaster University, Hamilton, Ontario.

elderly people's lives are not well understood and are the focus of this paper. Data drawn from a longitudinal study of home care recipients in Ontario, Canada are used to explore how elderly people negotiate and accommodate themselves to changes and retreats in home care.

The individualism characteristic of modern societies means that 'dependence' is demonised and the interdependencies inherent in human experience obscured (Sevenhuijsen 1997). Politically, individualism justifies the withering of collectively endorsed entitlements to support and the opening of previously public services to market forces (Broad and Antony 1999). Responsibility for wellbeing and security are left in the hands of individuals expected to navigate mixed economies of care as self-interested and atomised consumers rather than as citizens with shared interests, rights and obligations. This individualising ethos is compounded for older people by a dominant imagery of successful or positive ageing that enjoins them to age actively and self-sufficiently (Katz 2000).

For older people in need of care and assistance in Canada, these political and discursive conditions legitimate cuts to public health care and the offloading of care from hospitals to people's homes (Armstrong and Armstrong 1996, 1999; Canadian Centre for Policy Alternatives 2000). However, even as the federal, and many of the provincial, governments boast balanced budgets and vanquished deficits, community care (more accurately termed home care) has not been proportionally expanded or re-examined as an integral part of public health and social care. On the contrary, the federal government has chosen not to act on recommendations that home care be integrated into the publicly insured and universally accessible health care system (National Forum on Health 1997). Home care therefore continues to be subject to no national standards and to exist as an unmandated and ambiguous arena of provincial jurisdiction. For most provincial ministries of health, it has been the focus of quests for containment, rationalisation and privatisation.

In Ontario, the site of the research reported here, these quests have been taken up with particular ideological vigour. In 1996, the newly-elected conservative government introduced a system of 'managed competition' in home care, seeking to reduce public costs and enhance efficiency and consumer choice (Williams *et al.* 1999). This market-modelled system has much in common with managed care approaches in the United States and with community care reforms in the United Kingdom. The role of the public sector is confined to assessment and the contracting out of service provision to competing non-profit and for-profit home care providers. These activities are undertaken by 43

Community Care Access Centres (CCACs) distributed throughout the province. Case managers in each CCAC assess home care clients' eligibility and need, and co-ordinate packages of services drawn from contracted providers. Soon after the CCAC structure was implemented, upper limits to service allocation and rationing regulations were introduced (Government of Ontario 1999) and CCACs were charged with operating within tight and unpredictable budgets.

Eligibility criteria in this straitened home care market give priority to those with medically-defined needs: to people discharged from acute hospitals for treatment or rehabilitation at home, and to people with longer-term health problems that require medical monitoring or attention (Ontario Health Coalition 2001). People in need of long-term personal care and practical support, the populations of concern in this paper, are given lower priority and are gradually being rationed out of the system for all but the most minimal bodily maintenance. This medicalisation of home care generates particular jeopardies for the frail older people who dominate this category of need, most of whom are women. It is a pattern of home care targeting already found to be damaging in other jurisdictions where some of the human and economic impacts of gutting publicly provided social care are being noted (Means 1997; Sundstrom and Malmberg 1996; Thorslund, Bergmark and Parker 1997; Wistow and Hardy 1999).

Social care (variously termed personal care, domiciliary care, preventive care, home support) occupies what Twigg (2000: 107) illuminates as an ambiguous 'grey area' of service provision at the medical/social boundary in community care. Always the poor and the poorly understood relation to medical care, social care slips easily to the edge. It is associated with the daily activities of ordinary living (getting up, going to the toilet, washing, dressing, preparing and eating food, going shopping, washing clothes, maintaining a home). Against medicine's claims to scientifically-based treatment, cure and rehabilitation, the purposes and outcomes of social care are vague. Its association with the mundane and domestic means that it is easily overlooked, trivialised and pushed into the private domain of families or commercial care markets (Baldock 1997; Dalley 2001).

Elderly people in need of care at home are positioned in this precarious arena of social provision and at complex intersections between public and private, formal and informal, and independence and dependence. As a site of receiving formal care, the home is fraught with ambiguity. Home is thought to assure the care recipient greater power than could be attained in an institutional setting, as care providers enter not only as formal helpers but also as guests (Twigg

1997). Further, recipients still have around them the material props to biography and identity that are associated with home. Simultaneously, though, formal providers' very presence in the home signals an intrusion of public into private. Home care carries the contradictory potential both to support and undermine what home signifies. While the entry of home care may prove helpful, it also lays bare the reality of people's neediness and slipping capacities (Galivan 1992; Hurst-Rojiani 1994). Writing of elderly people living alone toward the end of life, Seale (1996: 75) notes how even 'neighbourly surveillance' can signify this slippage and jeopardize people's dearly-held reputations for independence. In the discursive terms of positive or successful ageing, this slippage denotes failure and the beginning of decline into the culturally shrouded realities of deep old age (Blaikie 1999).

Understanding how elderly people navigate and make sense of this compromised and tense social and physical space is limited. There is now a significant gerontological literature on older people's negotiations of daily life in institutional settings and on their everyday practices of constituting the self within them (Gubrium 1993; Hazan 1992; Willcocks *et al.* 1987). This body of work illuminates the complexities of sustaining and constantly revising a sense of self in the face of physical decline and the political jeopardies of relying on others' care. Much less is known about comparable processes of negotiating care and constituting self when the home is the site of care receipt.

Method

A longitudinal (1998–2001) study was undertaken to explore older people's experiences of receiving care at home. A purposive sample (Mason 1996) of women[1] relying on home care for extended periods was recruited through the newsletters of three community-based advocacy organisations concerned with the wellbeing of older people, through a number of related community groups concerned with long-term illness and disability, and by word of mouth through their memberships. Participants were not recruited through service organisations so that the research was clearly not associated with the care or resources upon which they relied. In locating sample members, a range of experience was sought in terms of health status, length of service receipt, social class, culture, and marital and family status.

Twenty of the women who took part in the study were aged over 65 and their experiences are the basis for the analysis developed in this paper. At the study's outset in 1998, they ranged in age from 66 to 92; five of them were aged under 75 and 15 were 75 and over. Participants lived in their own homes; 17 lived alone, two lived with their husbands and one with an adult child. They were all located in urban southern Ontario and fell into the catchment areas of six CCACs. They lived with a wide variety of chronic conditions and disabilities; many had multiple health problems. The practical limitations and challenges resulting from these conditions varied and generated a range of needs for assistance. At the beginning of the study, the length of their acquaintance with some form of care at home ranged from two to 20 years.

Participants' family and informal networks varied in terms of availability and emotional closeness. For five participants, family networks were practically non-existent. Eleven had more populated networks but no relatives who lived nearby or were easily available, so tended to rely on them for only occasional help or help in a crisis. The remaining four had more actively involved family caregivers. In terms of income, eight depended almost entirely on government transfers, so were poor, while 12 had higher incomes as a result of their own workplace pensions or the benefit of their husbands' pensions or insurance. All participants were white; 14 had been born in Canada, six were immigrants to Canada, and for four of them English was not a first language.

Over the three years of the study, there was some attrition in this original sample: two participants died, one moved from her home into institutional care, and two left their homes and could not be traced. The transferability of this sample of experience requires some qualification in terms of its narrow range of cultural diversity and its confinement to urban areas and to one Canadian province (Lincoln and Guba 1985). In the tradition of critical ethnography, however, it provides a point of entry for understanding the experiences of elderly people negotiating and accommodating themselves over time to rationed and unstable social care.

Participants took part in individual, semi-structured interviews twice a year and at additional points if their circumstances were changing in some way. In successive interviews, they spoke about a range of aspects of their unfolding lives: their home care arrangements and encounters, their health, their social surround (family, friends, community affiliations), their histories, aspirations, joys and worries. They related both their day-to-day practical activities and social exchanges, and the ongoing story of themselves and their responses to their material and social environments. With the participants' permission, interviews were taped and transcribed. In addition, detailed notes of phone conversations and field observations were kept. These transcripts and field notes formed the basis of the analysis.

Findings

Three accounts of negotiating and making sense of home care emerged from analysis of interview material and field notes. *Taking charge* was an active account of women successfully impressing their particular needs and identities on home care provision. *Pushed over the edge* was a vulnerable account of insufficient and depersonalised care in which participants felt themselves practically and emotionally out of control. In *Restraining expectations*, women adjusted silently to the shortcomings of home care, stoically making themselves smaller as they found their previous orbits and identities unsupported. Over the three years of the study, women did not speak statically within one or other of these accounts. They drew on the accounts with some fluidity and, in some instances, shifted from one to another over time.

Taking charge

Participants taking charge of home care described active efforts to control their situations and govern the terms under which care workers entered their homes and became involved in intimate aspects of their lives. Most reported initial reluctance to have 'strangers' coming into their homes but came to accept the logic or inevitability of outside help: 'After that fall and home care starting, I thought "OK", but I'm going to make this work for me'. To make it work, participants engaged in complex strategies to assert their command over their territories, a command imperilled by their own and others' judgements that they could not cope alone. Echoing others' research in this area (Rubinstein, *et al.* 1992; Seale 1996), two inter-related dimensions of this assertive work emerged: minimising exposure and making themselves known.

The entry of formal care providers into the home means that an external gaze is directed at what are, ordinarily, the most private arenas of people's lives. With respect to bodily exposure, participants spoke of ways in which they sought to limit this intrusion. One woman stressed that she did not really need her homemaker's help with showering and thus could set limits on her exposure:

> I don't need her to come into the, uh, washroom with me … to shower … I've got the washroom very well-equipped. But I keep the door open and I tell her: should I need her I'll call her and would she please come. I tell her when I'm going in.

Her physical boundaries were, thus, compromised only as far as not closing the bathroom door. Participants also set limits on the domestic territory into which they permitted a worker's entrance: 'Those closets and drawers in the bedroom … I tell them not to go in there. They're still mine'. Some established limits on intrusions into their privacy. One woman reflected that she would not want more help:

> It's enough, I like some privacy. I feel as though people's always in with me and I don't like that. I like to be quiet, I'm a quiet person … I have to have time alone. She (the cat) is the only one allowed in my territory.

Another participant refused more help in order to limit the social demands embodied by the home care worker:

> With home care coming, I've got to be up at 7.00 to get washed and have my breakfast, sort of to be ready for when they come, you know. And they keep saying you need somebody on the weekends. And I keep saying 'oh please, I don't think I could stand it'.

For this woman, being ready for when the home care worker came meant making herself 'presentable' for an outsider. Having a presentable public face and limiting outsiders' knowledge of the work and time involved in preparing that face was another facet of minimising exposure and asserting personal boundaries. In effect, she and other participants sought to shroud their needs and limitations. Thus, several spoke of 'tidying up' before their workers arrived: 'I didn't want her to see the place like this; what would she think?' Some were particularly circumspect and self-protective in describing their situations to their case managers during sporadic re-assessment visits, anxious to minimise their frailty and distinguish themselves from what the case manager of one referred to as 'nursing home material'.

> When she visits, she sees me sitting on a walker, doesn't realise I can't move about, take dishes from cupboards without dropping them … She'd have a fit, you know, she'd put me in a nursing home right away.

Determined to preserve their reputations as competent and coping, and to limit others' knowledge of their incapacities, women taking charge of home care were also intent on asserting themselves so that their home care fitted and respected them and their particularities. One woman showed me a letter 'written in anger' about her ever-changing homemakers:

> Please don't send me a young girl using the job as a stepping stone and inexperienced in homemaking. It's important to have consistent and compatible home support and someone who becomes familiar with our ways.

Another described how she made a point of 'teaching' her homemaker to cook in ways she deemed right and healthy. She linked her resolve to her lifelong attention to nutrition. 'Teaching' was for her a way of both making her preferences known and of impressing her biography on her situation. Two members of the sample engaged in the same processes of impressing their domestic preferences and habits on their situations though with different concerns. They described themselves respectively as 'always a poor housekeeper' and 'a lifetime packrat'. Despite feeling acutely the surveillance and disapproval of outsiders, both strove to ensure that their homemakers respected their particular boundaries and left their apparent disorder alone.

To stay in control of their surroundings, appearance and social relationships, women often engaged others' help. Participants with available family members turned to them for help with, for example, shopping for clothes and gifts, and help with housekeeping tasks that were outside their home care workers' limits, such as setting their hair, looking after houseplants or cleaning cupboards. Some participants paid for private help to sustain past patterns of living. For instance, one paid someone privately to help her shower in the evenings: 'I've always liked to shower at night, it's just not a morning thing and that's all the home care will do'. A participant with limited vision and mobility loved to cook for her family: 'It's my last claim to fame'. In order to continue doing so, she asked her apartment building doorman to read recipes and paid someone to take her shopping and to do 'a proper clean' in her kitchen. Some relied on informal sources of support (neighbours, friends) but only with certain kinds of small and occasional tasks.

And some negotiated the informal or unofficial assistance of paid care providers to maintain control and get their needs met in terms of their defining. For example, with her homemaker's complicity, one participant re-framed her case manager's designation of her weekly homemaker's visit for 'personal care' in favour of having some fresh-cooked food and some company while she ate. The meal and the sociability were more important to her than 'the magic bath' (the official condition for home care receipt, for which she substituted a sponge bath while standing at the sink). Others described ways in which their homemakers went beyond the formal bounds of their work, for instance, giving a home perm, taking them for a short walk, phoning in between visits or coming over in an emergency.

In short, participants taking charge of home care strove to ensure that care was tailored to their situations and needs and minimally compromised their senses of themselves. However, even as they took charge in this manner, participants were sometimes acutely aware of the fragility of their control. For instance, in our first two interviews, one participant described how she actively managed the detail of her days and the multiple sources of assistance on which she relied. She noted with pride that her family recognised her management skills and determination and called her 'the supervisor'. At the close of the second interview, however, she reflected soberly: 'But I know I'm living on the edge'. Soon afterward, she had another fall and her home care hours were cut. Her precarious control was shattered and she found herself pushed over the edge and out of control. The demands of taking charge proved too great and the discrepancy between need and care widened, producing a different, distressed account of receiving care at home.

Pushed over the edge

Experiencing themselves as pushed over the edge, participants felt exposed and unable to impress themselves on their situations in any way – conditions the very opposite of those established while taking charge. The lack of control that characterised this account was experienced in both practical and emotional terms; participants found themselves unable to influence their external environments and unable to hide their need and distress.

Women's sense of exposure was particularly heightened by the changes in home care workers that were commonly experienced during the study period. Ontario's new and unstable home care market continues to be characterised by shifting contractual arrangements, depressed wages, high turnover and labour disruptions (Ontario Health Coalition 2001). For study participants, changes of personnel meant that their bodies, their homes and their inability to manage aspects of both were exposed over and over again. One woman spoke with distress of the difficulty and demands of having 'successions of strangers' helping her with bathing and bowel treatments: 'You have these strangers coming in and looking after you in very personal places and you have to … you have no choice, that's the way it has to be done'. She and others spoke of how tiring they found it to explain to people what they needed and where things were kept.

Not being known by care providers was a central element of being pushed to the edge and it was experienced in a variety of ways. The inconsistency of home care providers exacerbated the affront. Participants felt diminished and disrespected at being expected to accept help from people unfamiliar with them: 'They send new girls and they don't even *know* you!'

The temporal organisation of home care work was also experienced as disrespectful and depersonalising. Participants found their workers driven by attention to the clock rather than by attention to them. Workers were expected to accomplish their practical tasks more quickly than before. With her homemaker's visit cut from an hour to half an hour, one participant with very impaired mobility protested: 'But no one can give me a bath in 30 minutes!' Another observed: 'Now, she (the homemaker) hardly has time to say hello'. Experiencing their workers as rushed and harried, participants came to feel so themselves:

> The girl I had last night, she gives half hours now. She comes here but then she's got other half hour people … and she hasn't got a car … And they're telling you about it and … it gets me all rattled up because I figure they're thinking, 'well, I'm here but I've got to be going'.

Several participants also described changes in the times at which workers came – changes driven by their employer's needs, not by attention to the rhythm of their own days: 'I'd prefer to stay up at night and sleep in the morning, but that's over now'. Some were given only approximate, wide bands of time commitments and felt themselves waiting all day, without control: 'They run your life. I may as well be in hospital'.

The tighter rationing and standardisation of home care was another facet of participants' experiences of being depersonalised. The tone of the case managers' rationing often communicated a damaging sense of personal erasure. For example, one woman described how a new case manager visited her and, without asking about her and her situation, explained the new 'guidelines' to which she was subject:

> The thing was they're having cutbacks because they didn't get any more money. That was the first thing: 'We're cutting everybody back. And you can have a shower once a week, twice a week if you're incontinent. When you're having your shower, there's fifteen minutes allowed for the girl to clean the kitchen and the bathroom – in fifteen minutes while you're having your shower'. It was, it was unbelievable!

Another participant was shaken when told that her new commercial meals-on-wheels provider would not adapt its food containers to accommodate the limits to her manual dexterity. She was told that they delivered a standard product and would not adapt to individual circumstances: 'They said no one else has complained, that I'd have to cope'. Capturing the impact of such rigidity, she observed: 'It's like being on an assembly line'. At such objectified moments, participants were given to understand that they had little or no significance as individuals, despite the standard policy rhetoric that home and community care hold the promise of highly personalised assistance.

Participants found that they could not count on assistance to be responsive to declines in their health or ability. After breaking her arm in a fall, one woman needed to wear a cast which, especially at the beginning, disturbed her already poor sense of balance:

> I wasn't entitled to any help at night to help me get undressed and prepared to get to bed or heat up my soup or something like that. That was it. And the government said: 'Well you should get family', but they're not always around, they're away or they work.

Besides not receiving needed increases in assistance, many participants experienced cuts in their existing allotments of home care. The cuts resulted initially from the provincial government's general funding restrictions and, later, from cuts to social care and home support made explicitly in order to prioritise care deemed medically necessary. These cuts were explained by case managers as fiscal inevitabilities. Accordingly, one participant's case manager reduced her homemaking visits from seven days per week to four:

> She just made the announcement. She didn't say to me 'are you any better?' On that day I was feeling really sick and there she just announces it, I'd been cut. And she was so severe about it, you know.

Such cuts forced some participants to ask others for help in ways they felt inappropriate. For instance, having cut her home care workers' visits, one woman's case manager urged her to ask a neighbour to assist her with needed eye drops. She reported feeling 'humiliated' at having to breach what she deemed proper social boundaries. Such cuts also undermined participants' ability to cope with even basic activities, and thus undermined their confidence: 'I'm seriously having to consider going into a nursing home, I wonder if it's my fear taking over'; 'How am I supposed to manage now? As it is, I'm only just keeping the house and myself together'.

Distress about barely 'keeping house and self together' was frequently voiced when participants felt pushed over the edge. Embarrassment about the condition of their homes was frequently voiced to me, as an outsider coming in and seeing what they felt to be untidiness and poor housekeeping: 'Look at this place, I'm ashamed of it'; 'I can't ask anyone here now – I'm too embarrassed'. Apologies and embarrassment about 'unkempt' personal appearances were common too: 'I can't get my hair permed any more, I look a fright'. 'I've no clothes, I wear the same things over and over and can't take care of things myself; the homemaker isn't allowed to do mending or anything'. 'I've just had to let myself go; it's shameful'. Another spoke of distress at not being able to entertain a guest properly:

> This lady (a childhood friend visiting the city) came and she, uh, she came right at noon time and I was so embarrassed because I couldn't make her lunch and I looked awful. My lunch was in the fridge, 'cause the girl had made it for me but I had nothing else to give her.

Not being in control of their appearances and their surroundings and not having the resources to create desired impressions of themselves was a deeply reducing experience for many. It engendered shame and self-criticism and, because it led women to stop inviting visitors into their homes, it deepened their isolation.

Feeling themselves jeopardised and not in command of their lives, participants variously voiced, anger, fear and depression in interviews. Significantly, they emphasised that they moderated expression of these feelings in other contexts. A few had directed anger at service providers or case managers in, for instance, challenging service cuts or asking for more consistent or better prepared workers. They noted, however, that this had to be done with care and strategy, that it was dangerous to 'bite the hand that feeds you'. Most stifled their emotions. For example, struggling with the after effects of a fall and a service cut, one woman told me in flat tones: 'But you mustn't complain, you know; people don't want to hear it, they'll avoid you'. When I invited her to complain out loud to me if she liked, she observed:

> I get depressed but I don't tell my friends or (my niece) or anything … you're the first person that I ever mentioned it … I don't usually bring it … think about it too much … what's the point? You know, I'm here and that's it.

At the end of the interview, she reminded me that this was told in confidence, that she would be 'mortified' if others in her life knew. Like others, she felt the impropriety of making her suffering known. The containment of distress and complaint emerged as a key feature in the third, self-restrained account of receiving home care.

Restraining expectations

In this third account of needing care at home, participants had no expectation that home care would adapt to them. Rather, they adapted themselves to it stoically by restraining themselves and their expectations. Women described both practical and self-reflective ways in which they resigned themselves to their inability to take charge and to the inevitability of letting go of past preferences and wishes. This resignation buttressed them against vulnerability and distress: 'You just have to make do. At least I'm still here at home and independent. And anyhow, I can't bear the thought of the alternative'.

This particular woman's comment followed a period in hospital, the loss of an old friend and several weeks of feeling exhausted and hopeless about her ability to manage again at home. For her, 'making do' consisted of changing the way she inhabited her home. She lived increasingly in her bedroom, concentrating needed objects and valued possessions around her. In this way, she both minimised the risks of walking and falling in the wider physical orbit of the house, and lessened the need for the living areas to be kept up – or at least, lessened her awareness of their neglect. She also stopped going out entirely, giving up a lunch club at a seniors' centre and attendance at church. Like subjects in Rubinstein and colleagues' research (1992), she and others gradually scaled down their environments and counted themselves out of the world around them.

They also scaled down or abandoned past preferences, activities and desires. For example, when the woman cited above knew that housekeeping assistance was to be cut off and that she could only expect help with a weekly bath, she adapted without complaint: 'I know she (the homemaker) is meant to clean round the bathroom afterwards so that'll have to do there. And I'll just have to live with the bedroom and kitchen in between my daughter's visits'. Another woman abandoned her longstanding practice of preparing a 'proper meal' each day, deciding that Meals on Wheels was 'sensible and realistic'. Another recognised that, despite a lifetime of careful attention to clothes, she would have to settle for sweat pants and a T-shirt every day: 'There's no one to see me anyhow'. And another resigned herself to lowered standards of housekeeping: 'So, I'll never have my mattress turned again; I suppose it doesn't really matter'.

A few participants referred to ways in which they neutralised or numbed themselves to the diminishment inherent in these accommodations. For example, of the repeated exposure resulting from changing care providers, one woman noted: 'If it's another new person for my bath, I just steel myself. I say, "think of it like a nurse or doctor"'. Another accommodated her unkempt appearance by rendering it invisible: 'I just avoid looking in the mirror – it's easier that way'. Despite being necessitated by service cuts, some women framed such accommodations as if they were of their own prompting: 'I decided it was time to close off the upstairs'; 'I decided my cooking days were really over … it was time'. Some found other ways to rationalise them and neutralise their impact. For example, while sometimes dispirited at her mounting isolation and the successive practical accommodations that heightened it (giving up a motorised scooter, no longer using assisted transit, not inviting friends in), one woman asserted: 'But it's OK really; I've always been a loner, even as a child'. Another noted that her support worker's early arrival each day, a schedule governed entirely by her agency's needs, ran counter to the normal rhythm of her days, but she reflected: 'Maybe it's just as well though … I've become a bit of a sloth over the years'. In effect, the constraints of others were re-framed and taken on as their own.

This kind of re-framing of what might have been the object of complaint into acceptable terms was often expressed altruistically, as a way of showing care or consideration for others. Several participants noted that they scaled down their lives or abandoned aspirations in order to relieve their families or friends:

> My daughter can't be coming over with shopping and that, with all she's got on, and she worried about me at the stove. So I tell her I like the Meals on Wheels – it's easier for her to think that. I don't want her worrying.

Participants also made accommodations out of consideration or concern for formal care providers. To a case manager who had informed her of budget pressures and future service cuts, one reported her reply: 'Since you've said how hard it is for you, I won't take any more'. Despite finding that some care workers were untrained or poorly trained, many participants accommodated their shortcomings and spoke protectively of them. One described a barely palatable meal: 'But I ate it; I didn't want to hurt her feelings'. Another found her worker quite slow and unskilled: 'I give her 'A' for effort though … she tries and I know she needs the job'. Similarly, a woman who needed help in getting to bed noted that because her new weekend worker had no training in lifting, each night was a struggle for her: 'But it's all right! She's young and gentle and lovely to look at. It doesn't matter'. Even as they articulated such shortcomings, they were quick to disavow complaint: 'I'm not criticising, mind you; I wouldn't want you to think I'm complaining'; 'That's not a complaint, you know, I'm very grateful'. Gratitude for what was received was a common element in these resigned accounts.

Some participants accepted poor or insufficient care and restrained their own demands because they felt the government's straitened economic circumstances required it. For example: 'We all have to tighten our belts, everyone's got to do their bit'. For this woman, 'doing her bit' offered an avenue for participating in and contributing to the wider world from which she was now practically excluded. It enabled her to assert a valued identity as independent and contributing, even as it meant restraining herself and subordinating her own needs. She voiced a sense of moral superiority over her sister: 'She'd just whine and complain. She's one of those old people who expect too much, expect everything to be done for them'. Others explicitly aligned themselves with the constraints of the public purse, for example by approving case managers' rationing and gate-keeping functions: 'She doesn't stand any nonsense this girl; she's the right girl in charge … I mean, this is costing the government money!'

By making do and accommodating home care's insufficiencies in others' interests, participants effectively counted themselves out of public consideration. They absorbed the government's, service providers' and families' constraints as their own, and saw themselves alone as responsible for managing. A participant who fell in her bathroom between our third and fourth interviews illuminated this process. Wanting at all costs not to go into hospital, she did not call her doctor after her fall. She also did not inform her case manager: 'I saw no point. She said they couldn't afford to give more the last time'. Having no expectation that she would be able to attract helpful attention from her case manager, she stifled an expression of need. She judged that she had broken no bones and struggled on doggedly and alone. Similarly, another woman whose deteriorating vision made everyday tasks a mounting challenge took the government's budget cuts as given:

> I wouldn't ask for more help though. They've already told me they've no money, there'd be no point. I'll never ask again. I must just manage by myself. I must be independent.

Stoic restraint of expectation and dogged 'independence' were often linked by participants to their determination to avoid institutional care at any cost. No one in this sample spoke of the prospect of a nursing home with equanimity: 'I'd have to be three-quarters dead to go into one of those places'; 'I'd rather be dead'. Participants described how abundantly their determination was reinforced by media accounts of substandard nursing homes, by the difficult experiences of friends and acquaintances, and by their home care workers' stories about poor institutional working conditions and care: 'Lots of days I feel I can't stay (at home) but then you hear all these bits and pieces and you think maybe it's not so bad here'.

This understanding of what lay ahead if they failed to accept their narrowing lives motivated participants to restrain their expectations and contain complaint. Nonetheless, the tensions underlying this restraint were at times apparent. For example, in response to being asked if she thought that years of receiving home care had changed her at all, one woman responded cryptically: 'It makes a different person of you ... yes, more miserable'. On closing an interview with another participant, who had spoken throughout of stoically reducing her world and herself, I expressed the hope that the months ahead, before we met again, would be all right for her. She replied quietly: 'But, there is *nothing* to hope for. I just hope I don't get any worse and am not a burden to my family'.

Discussion

The three accounts of home care found in this study offer a glimpse of the complexities and tensions of home care receipt in the face of its retreating public provision. Participants' accounts accord closely with Barry's observation that: 'the work of shaping needs to available care provision requires emotional and physical effort' (1995: 372). Indeed, the participants revealed the enormous resourcefulness, determination and grace that they summoned in their daily lives in order to shape their needs to unstable and diminishing home care provision.

The three accounts of negotiating care at home illuminate too the impacts of broad political and social changes on personal experiences of ageing and the need for support to live at home. They reveal the ways in which elderly people's selves are implicated in their negotiations and are a reminder that identity is: 'an important crossroads between the experience of self, day-to-day communication and expectations arising from social policies' (Biggs 1999: 153). Taking charge, women felt able to influence the care they received in ways that buttressed valued and continuing identities: 'I've always prided myself on keeping a good home'; 'I've always liked to be in charge'. Pushed over the edge, influencing the external conditions of their lives or sustaining desired images of themselves proved beyond them: 'These clothes, the mess, it's not me you know'; 'I try to tell myself to make the best of it but … it's like they just want to keep me fed and watered here, that's all'. Restraining expectations, women accepted their inability to influence the external surround and, instead, withdrew and adjusted themselves to it psychologically: 'So it's come to this but I am surviving, I'm still here'.

The interviews themselves were, of course, social encounters in which these identities were constituted. Accounts of taking charge and assertions of robust identities tended to dominate the early interviews. Participants were meeting an unknown researcher – an able-bodied, middle-aged, professional woman – and, perhaps unsurprisingly, they emphasised their competence and active quests for independence. Their accounts in later meetings tended to include a wider range of feelings. Being pushed over the edge was the hardest account to voice. It represented the most conspicuous failure to be self-reliant; neediness and precariousness were most exposed and participants often spoke with raw expressions of distress, anger, shame and fear. At the end of such exchanges, I was often asked for reassurances about anonymity and confidentiality. Others' knowledge of participants' exposed suffering would jeopardise their reputations and engender shame, a signal of anxiety about the integrity and adequacy of self

(Giddens 1991: 65). Conversational 'repair work' often followed such exposures. Transcripts show me and participants working to patch over vulnerability and restore the talk to more speakable and presentable topics. Speaking stoically of restraining expectations, participants often sounded flat and subdued, but occasionally expressed some pride at their successful exercise of self-restraint – pride deriving, perhaps, from the knowledge that they conformed to the cultural expectation that 'decrepitude' be willingly kept out of sight and exclusion borne without complaint (Tulle-Winton 1999: 290).

Participants with different knowledge and experience of illness and disability expressed and saw themselves in different ways. For most, infirmity was a new experience, known for the first time in old age. They spoke from the edge with difficulty and often with heavy self-censorship. In contrast, four participants who had known disability from childhood or early adulthood more readily expressed anger and complaint at being pushed to the edge and did not hide their suffering. They spoke of their vulnerabilities with less restraint and, while aware of the need for strategy in revealing themselves, they seldom voiced shame. For example, a 70-year-old woman who had lived since birth with a neurological disability spoke with a clear analysis of her social location and the origins of her vulnerability: 'You see, they choose disabled and elderly because they don't have a strong voice and if they're going to cut money that's the way to do it'. She had for many years been actively engaged in organised advocacy for people with disabilities and drew on a political discourse about collective rights and equity.

Participants' abilities to speak about their experience of home care and about their options for adjusting to it were further shaped by the material and symbolic resources at their disposal. Having family members who could supplement insufficient or reduced care was, as is well recognised, a key to sustaining valued activities and for fending off diminishment. Almost half of this sample (eight) had few or no family supports to call on, because of one or more of small kin networks, their geographical dispersal, or longstanding estrangements. Having the financial means to pay privately for additional services also allowed some people to meet needs that would be otherwise unattended. However, reflecting the distribution of income among older women in Canada (National Council of Welfare 1997), almost half (eight) of this study's participants were poor, so completely unable to engage in the private market. Of the remainder, some could just afford small 'dignifying necessities' (Rubinstein *et al.* 1992: 146) such as more thorough cleaning, shopping, hairdressing, care of clothes and being escorted on trips.

Possession of interpersonal and bureaucratic skills enabled some participants to take charge of home care or to control the contraction of their worlds. Such skills allowed them to engage care providers constructively and negotiate successfully with the organisations that employed them. These skills and resources are likely to be associated with class and cultural divisions and to be unevenly distributed. Indeed, some participants explicitly linked their lack of such skills to their social locations and identities. One participant noted that she had been brought up 'roughly', had always been 'blunt' and knew her home care workers thought her 'difficult'. She was unable to present herself as a rewarding client by engaging in 'emotional labour in reverse' (Twigg 2000: 207). A woman who termed herself fat, another who identified as lesbian, and another who knew she was deemed 'disfigured', attributed poor or unkind treatment to prejudice about their personal characteristics.

Unsurprisingly, then, the damaging consequences of across-the-board rationing and withdrawal of public social care fell inequitably in this sample. Concerns about such inequities and the dynamics of their unfolding are already clearly identified in Britain where, after a decade of community-care reforms, observers warn of the growing 'care divide' (Means 1997), the age-based discrimination embedded within it (Dalley 1998: 14), and the dangers of 'covert' privatisation (Dalley 2001).

The covertness of privatisation in community care poses enormous challenges for mobilising public attention and for working toward more adequate and equitable provision. Without explicit policy declarations and without debate, long-term care is gradually slipping out of the public health care system in Canada (Canadian Centre for Policy Alternatives 2000). This study has sought to illuminate the cumulative costs to old people of this slippage; the costs to them of home care's depletion and withdrawal. These costs are borne out of sight in the privacy of their homes. Their articulation is suppressed by dominant cultural images that prize independence and silence expectation of public support. The accounts elicited in this study expose home care's front line as a complex site of struggle for agency and identity – a struggle in which older people engage with inventiveness and determination but also with dwindling supports, few witnesses and in mounting isolation. In order to work toward systems of social care that respect and sustain elderly people's identities and enable their social participation, it is crucial that these presently hidden experiences of needing help at home be brought forward and actively included in debates about policies and practices in home care.

Acknowledgements

The work reported here was supported by research grants from the Social Sciences and Humanities Research Council of Canada (Women and Change #816-98-0042) and the National Network on Environments and Women's Health (a Centre of Excellence in Women's Health funded by the Women's Health Bureau of Health Canada). For their comments on an earlier version of this paper, I am grateful to Chris Sinding, Lynn Kearney, Roy Cain and Vivienne Walters.

NOTE

1 The study focused exclusively on women: especially at more advanced ages, women make up the majority of home care users and gendered assumptions about dependency, bodily frailty and citizenship generate particular jeopardies for women (Wilkins and Park 1998).

References

Armstrong, P. and Armstrong, H. 1996. *Wasting Away: The Undermining of Canadian Health Care*. Oxford University Press, Toronto.

Armstrong, P. and Armstrong, H. 1999. *Women, Privatization and Health Care Reform: The Ontario Scan*. National Network on Environments and Women's Health, York University, Toronto.

Aronson, J. and Neysmith, S. M. 2001. Manufacturing social exclusion in the home care market. *Canadian Public Policy*, **27**, 151–65.

Baldock, J. 1997. Social care in old age: more than a funding problem. *Social Policy and Administration*, **31**, 73–89.

Barnes, M. 1997. *Care, Communities and Citizens*. Longman, London.

Barry, J. 1995. Care-need and care-receivers: views from the margins. *Women's Studies International Forum*, **18**, 351–74.

Biggs, S. 1999. *The Mature Imagination: Dynamics of Identity in Midlife and Beyond*. Open University Press, Buckingham.

Blaikie, A. 1999. *Ageing and Popular Culture*. Cambridge University Press, Cambridge.

Broad, D. and Antony, W. 1999. *Citizens or Consumers? Social Policy in a Market Society*. Fernwood, Halifax, Nova Scotia.

Canadian Centre for Policy Alternatives. 2000. *Without Foundation: How Medicare is Undermined by Gaps and Privatization in Community and Continuing Care*. CCPA, Vancouver.

Dalley, G. 1998. *Defining Difference: Health and Social Care for Older People in the 1990s*. Centre for Policy on Ageing, London.

Dalley, G. 2001. The Passive Privatisation of Social Welfare Services for Older People in the U.K. Paper presented at the 17th World Congress of the International Association of Gerontology, Vancouver.

Galivan, H. 1992. Care in the community: issues of dependence and control – the similarities between institution and home. *Generations Review*, **2**, 9–14.

Giddens, A. 1991. *Modernity and Self-Identity: Self and Society in the Late Modern Age*. Stanford University Press, Stanford.

Glendinning, C. 1998. *Rights and Realities: Comparing New Developments in Long-term Care for Older People*. Policy Press, Bristol.

Government of Ontario. 1999. *Provision of Community Services*. Ontario Regulation 386/99 made under the Long Term Care Act 1994. Gazette of Ontario, Toronto.

Gubrium, J. F. 1993. *Speaking of Life: Horizons of Meaning for Nursing Home Residents*. Aldine de Gruyter, New York.

Hazan, H. 1992. *Managing Change in Old Age: The Control of Meaning in an Institutional Setting*. State University of New York Press, Albany.

Hurst Rojiani, R. 1994. Disparities in the social construction of long-term care. In Kohler-Riessman, C. (ed.), *Qualitative Studies in Social Work Research*. Sage, Thousand Oaks, California, 138–52.

Katz, S. 2000. Busy bodies: activity, aging, and the management of everyday life. *Journal of Aging Studies*, **4**, 135–52.

Lincoln, Y. S. and Guba, E. G. 1985. *Naturalistic Enquiry*. Sage, Newbury Park, California.

Mason, J. 1996. *Qualitative Researching*. Sage, London.

Means, R. 1997. Home, independence and community care: time for a wider vision? *Policy and Politics*, **25**, 409–19.

National Council of Welfare. 1997. *Poverty Profile 1995*. Ministry of Supply and Services, Ottawa.

National Forum on Health. 1997. *Canada Health Action: Building on the Legacy*. Final report of the National Forum on Health, Ottawa.

Ontario Health Coalition. 2001. *Long Term Care – in Limbo or Worse?* Ontario Health Commission, Toronto.

Rubinstein, R. L., Kilbride, J. C. and Nagy, S. 1992. *Elders Living Alone: Frailty and the Perception of Choice*. Aldine de Gruyter, New York.

Seale, C. 1996. Living alone towards the end of life. *Ageing and Society*, **16**, 75–91.

Sevenhuijsen, S. 1997. Feminist ethics and public health care policies. In DiQuinzio, P. and Young, I. M. (eds), *Feminist Ethics and Social Policy*. University of Indiana Press, Bloomington, 49–75.

Sundstrom, G. and Malmberg, B. 1996. The long arm of the welfare state shortened: home help in Sweden. *Scandinavian Journal of Social Welfare*, **5**, 69–75.

Thorslund, M., Bergmark, A. and Parker, M. G. 1997. Difficult decisions on care and services for elderly people: the dilemma of setting priorities in the welfare state. *Scandinavian Journal of Social Welfare*, **6**, 197–206.

Tulle-Winton, E. 1999. Growing old and resistance: towards a new cultural economy of old age? *Ageing and Society*, **19**, 281–99.

Twigg, J. 1997. Deconstructing the 'social bath': help with bathing at home for older and disabled people. *Journal of Social Policy*, **26**, 211–32.

Twigg, J. 2000. *Bathing – The Body and Community Care*. Routledge, London.

Wilkins, K. and Park, E. 1998. Home care in Canada. *Health Reports*, **10**, 29–37.

Willcocks, D., Peace, S. and Kellaher, L. with Ring, A. 1987. *Private Lives in Public Places*. Tavistock, London.

Williams, A. P., Barnsley, J., Leggat, S., Deber, R. and Baranek, P. 1999. Long-term care goes to market: managed competition and Ontario's reform of community-based services. *Canadian Journal on Aging*, **18**, 125–53.

Wistow, G. and Hardy, B. 1999. The development of domiciliary care: mission accomplished? *Policy and Politics*, **27**, 173–86.

Accepted 17 March 2002

Address for correspondence:
Jane Aronson, School of Social Work, McMaster University,
Hamilton, Ontario, L8S 4M4, Canada.
e-mail: aronsonj@mcmaster.ca